Title: Evaluation of birth outcomes for high-risk women enrolled in New York State's Community Action for Prenatal Care Initiative: a collaborative effort

Health department/organization: New York State Department of Health
AIDS Institute

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Goal: Linkage to and maintenance of care for HIV-infected women

Program type: Community outreach

Collaborators: HIV/AIDS surveillance

Background/Objectives

To evaluate the birth outcomes of high-risk pregnant women recruited into prenatal care through the Community Action for Prenatal Care (CAPC) Initiative, the New York State Department of Health (NYSDOH) matched intake data collected on the local level with existing state-held databases. Alternative methods of outcome evaluation, (e.g. longitudinal approaches and case studies) could not be implemented due to resource limitations.

CAPC is a comprehensive initiative designed to decrease adverse birth outcomes, including perinatal HIV transmission and low birth weight, among high-risk pregnant women by recruiting them into prenatal care. CAPC operates at the New York City Correction Department facility on Rikers Island and in 4 target areas composed of selected ZIP codes in the Bronx, Brooklyn, Manhattan, and Buffalo. Selection of target areas was based on the percentage of women delivering with no prenatal care and on newborn HIV seroprevalence rates. A lead agency, identified in each target area, is charged with coordinating the activities of a local coalition including implementation of a comprehensive model of service delivery. Key components of the model are local planning, recruitment/referrals, intake and transitional case management, and user-friendly prenatal systems. A client may enter CAPC through a number of pathways: outreach by specially trained outreach workers, lead agency sponsored outreach events, agency referral, word of mouth, and social marketing. The goal of the social marketing campaign is to generate calls to the CARE Helpline, a CAPC-specific hotline which is answered by a live operator 24 hours a day/7 days a week. The client becomes a CAPC intake when it is verified that she completed her first prenatal care or case management appointment. Each lead agency is responsible for collecting intake information from the outreach workers and from other recruitment activities, then submitting this information to the NYSDOH.

There were significant obstacles to overcome when matching CAPC data to state-held databases. The specially trained outreach workers often begin to fill out the intake form in the field, which can compromise the data, causing difficulty in data entry and analysis. Matching the client's last name by hand was a laborious process requiring manpower that was not always

available. Confidentiality issues required data-use agreements that were lengthy to acquire. In addition, there was a considerable time lag for birth and HIV data to become available.

Methods

Key performance indicators for all CAPC women include prenatal care utilization, HIV testing history, and birth weight. Additional indicators for HIV-positive pregnant women enrolled in CAPC include receipt of antiretroviral therapy and mother-to-child HIV transmission. In collaboration with the Bureau of HIV/AIDS Epidemiology, the AIDS Institute matched CAPC intake data with the following existing NYSDOH databases: Vital Records (Birth Certificate), Comprehensive Newborn HIV Testing, and Perinatal HIV Surveillance. Birth certificate data provided birth outcomes (birth weight and severe neonatal outcomes), date of birth, and prenatal care utilization. Matching information with the Comprehensive Newborn HIV Testing Program database yielded maternal HIV testing history and HIV status. Finally, matching information with HIV Perinatal Surveillance data provided information on receipt of preventive therapy by HIV-infected mothers and their newborns and HIV transmission status.

Results

Intake data for 2001-2003 indicate that 1,427 high-risk pregnant women were enrolled in CAPC and connected to prenatal care and case management. To date, almost 700 enrollees (699 or 49% of intakes) had live births and were successfully matched to department databases as described above. The remaining enrollees may have moved out of state, changed their names, elected to terminate, or miscarried. The number in each category is unknown. Review of birth weight data revealed that 88% of CAPC women delivered normal birth weight infants (>2500 gms) compared to 91% of all women giving birth in the target areas. Prenatal HIV testing rates were equivalent (87%) between the 2 groups. Twenty-nine (4.1%) of delivering CAPC women were HIV-positive, compared to 1% in the target areas. Of the exposed infants, 1 is known to be HIV positive, 26 are confirmed to be non-infected and 2 infants are indeterminate and will receive follow-up.

Conclusions

Although there were significant challenges due to incompatibility of NYSDOH files and confidentiality issues, matching intake data with existing state-held databases proved useful in evaluating birth outcomes for women enrolled in the CAPC program. The challenge of collecting data from field-based outreach workers was met by seeking their advice in developing the intake form and continually improving the form to reduce variance in interpreting data elements. In addition, the AIDS Institute provides training to outreach workers and the lead agencies to improve quality control on the local level. The collaboration between the AIDS Institute, lead agencies, outreach workers and surveillance partners will facilitate future studies to demonstrate the impact of the CAPC program.